

**Lyme Disease Advisory Committee
Minutes of the August 7, 2001, Meeting
Department of Health Service, Sacramento**

The fourth meeting of the Lyme Disease Advisory Committee (LDAC) was held on August 7, 2001, in Sacramento, California.

Committee members present:

Jean Hubbard, Lyme Disease Resource Center
Vicki Kramer, Ph.D., California Department of Health Services
Robert Lane, Ph.D., University of California, Berkeley
Lee Lull, Lyme Disease Support Network
Susie Merrill, Lyme Disease Support Network
Scott Morrow, M.D., California Conference of Local Health Officers
Christian Parlier, Lyme Disease Support Network, attending via speaker phone
Raphael Stricker, M.D., California Medical Association

Other attendees:

Anne Kjemtrup, D.V.M., Ph.D., Department of Health Services
Approximately 40 people including representatives from the interested public and several public agencies.

I. Opening Comments

The meeting was called to order at 10:05 by Dr. Robert Lane, Chairman.
Mr. Parlier attended the meeting via speakerphone.

II. Review minutes of 4/27/01 meeting (approved 7/02/01)

Dr. Lane noted that committee members approved the minutes of the LDAC meeting held on April 27, 2001, via email on July 2, 2001. He asked if there were any additional comments on the minutes. Ms. Hubbard summarized a conversation between her and Dr. Kjemtrup concerning the minutes revision and approval process. They had agreed that: a) should Dr. Kjemtrup not retain a revision offered to the minutes, she would send her reasons to all LDAC members, and b) possible misunderstandings can be discussed via phone. A report of that conversation, with any resulting changes to the minutes, will be emailed to the full committee. Dr. Morrow expressed his continuing interest in being able to observe details of the revision process as it evolves. Dr. Kjemtrup clarified that all suggested revisions, comments, etc., would be tracked within the minutes attachment. Dr. Morrow moved that the minutes approval process proceed as described above, including a two week approval time with a follow-up phone call to nonresponders. Dr. Stricker seconded the motion and the

committee unanimously approved the minutes. Dr. Kjemtrup further noted that the minutes from the first two meetings were approved to be posted on the Division of Communicable Disease (DCDC) Web site (<http://www.dhs.cahwnet.gov/ps/dcdc/html/disbindex.htm>) and the minutes from the third meeting are currently being formatted for posting. The minutes will be available on the web site shortly.

III. DHS progress report: Review and discussion

Dr. Kjemtrup reviewed the activities of the Vector-Borne Disease Section (VBDS) concerning tick-borne diseases from April to August 2001.

- 1) Five talks were given by VBDS Public Health Biologists to various public agencies:
 - a) Navy Environmental Health Conference: "Vector-borne diseases in California-a review". Invited talk given by Mark Novak to approximately 30 attendees.
 - b) Mariposa County Extension Pest Control Operators as part of a continuing education program: "Vector-borne diseases and their prevention". Invited talk given by Mark Novak to approximately 30 attendees.
 - c) A campground concessionaire group that covers the California national forests from Lake Tahoe through the southern Sequoia National Forest: "Vector-borne disease risk at campsites and public use areas". Alec Gerry contacted this group and gave the talk to approximately 60 attendees.
 - d) A United States Forest Service (USFS) volunteer fire lookout group in southern California: "Vector-borne disease risks for USFS volunteers". Alec Gerry contacted this group and gave the talk to approximately 13 attendees.
 - e) Safety officers of Pacific Bell in San Francisco: "Lyme disease in California, protection and prevention". Lucia Hui was contacted by this group and gave the talk to ten safety officers.
- 2) Three talks were given by VBDS Public Health Biologists to various private groups including:
 - a) Backcountry Horsemen of Los Padres National Forest. Dick Davis was invited to give this talk on ticks and tick-borne diseases to approximately 40 attendees.
 - b) A zoonosis class at California Polytechnic, San Luis Obsipo. Dick Davis was invited to give a lecture on ticks and tick-borne diseases as well as lead a field trip to collect ticks to approximately 15 students.

- c) The Lyme Support Group of the mid-Peninsula, Mountain View: “A patient’s perspective of Lyme disease in California”. Lucia Hui was invited to give this talk. Twenty people attended.
- 3) Surveillance activities included flagging for adult *Ixodes pacificus* in Alpine County in May. No *I. pacificus* ticks were found.
- 4) Other activities included the establishment of a tick dissection / direct fluorescent antibody test protocol specifically for the investigation of *Borrelia* genetic diversity, and continuation of planning for the VBDS laboratory at the DHS Richmond, California facility, which is under construction.

Ms. Hubbard requested a written version of the report given by Dr. Kjemtrup, including credit to the person who gave the talk, how the group was contacted, and stating how many people attended the talk. Dr. Kramer responded that this information will be updated in the minutes (see above) and included in VBDS activity summaries at subsequent LDAC meetings

Dr. Lane added a brief update on his collaborative risk-assessment studies in Mendocino County, California. He began by mentioning that two of his postdoctoral students (Lars and Becky Eisen), a public health biologist from VBDS (Marty Castro), plus himself, are in the process of conducting an in-depth investigation aimed at determining the potential risk of human exposure to spirochete-infected nymphal western black-legged ticks (*Ixodes pacificus*) at nine widely spaced sites. Sampling for nymphal ticks is being performed biweekly in leaf-litter areas in mixed hardwood forests from spring to fall in several habitat types and climatic zones. On average, nymphal infection rates average about 5-15 percent in most sampling areas, but site-specific infection rates may range as high as 41 percent. Also, tick-infection rates and the abundance of spirochete-infected nymphs can vary significantly within and between properties, as well as between years. Dr. Lane emphasized that despite the importance of these kinds of data, the investigation is being undertaken in just one county, and similar kinds of data generally are unavailable for the other 57 California counties. The reason so few comparable studies have been done is because the combined field and laboratory research is quite expensive and must be funded by large grants to cover transportation, personnel and laboratory costs. Dr. Stricker asked if Dr. Lane is trying to determine whether ticks are co-infected with other tick-borne disease agents. Dr. Lane replied in the affirmative and mentioned that members of his research program currently are focusing on ticks, not rodents. He also noted that in the eastern U.S., researchers have found that deer ticks (*I. scapularis*) not infrequently are found infected with the agents of Lyme disease and the human granulocytic ehrlichiosis (HGE) agent. Dr. Kramer added that, at a study site in Sonoma County where VBDS had investigated woodrat infection with *B. burgdorferi* and the HGE agent, 5 of 11 woodrats (45 percent) were coinfecting and one was positive for *B. burgdorferi* only. Dr. Lane reminded the committee that, although a tick may test negative for *B. burgdorferi*, it still could

be infected with other tick-borne disease agents such as other rickettsiae and the virus that causes Colorado tick fever.

III. “High Hopes from the CA Lyme Disease Support Groups”: discussion of support group document

Ms. Lull had collaborated with many Lyme disease (LD) support groups in California to produce a document that she introduced at the last meeting (4/27/01) entitled, “High Hopes from the CA Lyme Disease Support Groups”. (Document is Appendix I) Ms. Lull stated that there are 12 LD support groups in California, and that, just in the last few months, three new groups have formed, two of which have asked that their signatures be appended to the “High Hopes” document. Dr. Kjemtrup thanked the LD support groups who had given her contact information because it helps her get the minutes of LDAC meetings out to them. Dr. Lane added that he thought the High Hopes document expressed patient concerns very well and had made the committee even more aware than they had been about the problems in California, especially about physician fears. He went on to say that he and the committee appreciate the contributions and hard work of Ms. Lull, Ms. Hubbard, Ms. Merrill, and Mr. Parlier on behalf of the LDAC, and that he sincerely felt that LD support groups were well represented on the committee by them.

Ms. Lull noted that the real reason people are here for this meeting is because Lyme disease is still going undiagnosed and untreated in California, and because patients count on DHS to help them. She said the most troubling problems are the reluctance of physicians to even consider a diagnosis of LD and their unwillingness to treat particularly disseminated and late LD. Doctors refuse even to test for LD, and are disdainful even of clear evidence of *B. burgdorferi* infections such as the presence of an EM. It is important to recognize the disease early in the infection process when it is most treatable.

She stated that it appears that physician fear of persecution by medical boards, and pressures from insurance companies and HMOs may be the source of under-diagnosis and under-treatment. She pointed to the systematic investigations by the New York State Medical Board of highly respected physicians who treat symptomatically as an example of a consequence that physicians fear. She noted that physicians in other areas of the East Coast, and in Michigan, Texas and Oregon as well, had lost their licenses or been told they could no longer treat Lyme patients. She noted that there are academicians who take money from insurance companies to state that a patient they’ve never examined does not have LD, and others who state that the real problem with LD is “Lyme anxiety”, not its morbidity.

Dr. Stricker added that all this has created anxiety in physicians as well, so that they do not want to deal with the disease and don’t want to learn about it. He warned this was an obstacle the committee will have to address, and that the

urgency of the issue for doctors would likely increase as more and more lawsuits are brought against physicians for missing a LD diagnosis.

Ms. Lull emphasized that DHS needs to help the situation by addressing the ability of the spirochete to persist after treatment. She noted that there are scientific studies that clearly show *B. burgdorferi* persistence. She asked those present who continue to have LD in spite of treatment to raise their hands. A majority did so, including members of the LDAC. She stated that almost every patient at the meeting has been treated with more antibiotics, over a longer period of time, than Dr. Klempner's study¹ ever dreamt of, and most significantly, that almost all have improved and regained functionality. She called attention to the fact that what DHS chooses to stress or not stress in their educational efforts significantly impacts the medical community's attitudes and beliefs about this disease.

She noted that any educational offering that speaks in absolutes about this disease is misleading its audience. We just don't know enough.

She then introduced four motions to the committee. Her first three motions focused on making information about tick infections available to the public – via newspapers, DHS' website and tick warning posters. She moved:

- 1 Because newspaper articles offer the best publicity to the broadest range of people, we would like to advise DHS to strongly urge all CA public health laboratories, in writing, to notify their local press each time an infected tick is identified, including ticks submitted by individuals. We believe that this would significantly increase awareness at the local level.
- 2 We recommend that DHS post on their website a color-coded map of California depicting counties where infected ticks have been found.
- 3 We recommend that DHS strongly urge, in letters to all state, local or federal parks and lands where infected ticks are found, that they post warning signs in prominent places and have Lyme brochures available for public education at these sites.

The committee generally agreed that getting tick infection data to the public via local media would be valuable.

Mr. Parlier suggested that DHS facilitate press reporting by writing a standard press release to forward to the testing labs. The labs could then release information to the press when they had a positive test result. Information about tick infectivity could also be forwarded to DHS, who could disseminate information to the press as well.

¹ Klempner, MS *et al.* Two controlled trials of antibiotic treatment in patients with persistent symptoms and a history of Lyme disease. New England Journal of Medicine (NEJM) 2001 Jul 12;345(2):85-92

Dr. Kramer agreed that, while a prewritten press release is a reasonable approach, putting out a press release each time a positive tick is identified could actually desensitized the press to LD. She suggested that press statements be targeted for timely releases, such as during the height of tick season. Currently DHS puts out only one press release on tick-borne diseases in the spring; however, the LDAC committee at past meetings has recommended two press releases, one in the fall and one in the spring. This is planned. Dr. Kramer also suggested that DHS could recommend to public health laboratories that test ticks for individuals that they should inform their public health officer or local vector-control agency when a positive tick is identified, or at least submit a periodic summary of their tick-testing data to the appropriate public health agency. Drs. Morrow and Kramer pointed out some of the difficulties potentially attendant to posting data acquired from public health labs. Only a small number of laboratories test ticks, and few record the county of origin of ticks submitted to them by individuals. Dr. Kramer noted that the data now in the DHS tick database are somewhat limiting because they reflect convenience samples of ticks, not ongoing surveillance. Dr. Lane commented that the only county where long-term surveillance has occurred is in Mendocino County where his group has performed extensive studies and demonstrated that tick infection rates can vary extensively over time and space. Ms. Lucia Hui, the VBDS biologist maintaining the database, explained that the DHS tick database contains only data derived from ticks that were flagged and tested as part of surveillance, thus it is clear from where the ticks originated. The database does not contain testing results of ticks removed from people and submitted to public health labs. A few local public health labs that test ticks already forward their data to her when they find a positive tick. To date DHS has surveyed 45 of California's counties, testing adult ticks, and has found infected ticks in 36 of those counties. Published data are also included in the database, establishing tick infections in five other counties. Therefore, of the counties studied so far, infected ticks have been found in 41. She said that all tick-infection data in the database are from ticks tested by standard tests – DFA, IFA, culture, and PCR.

Dr. Kramer offered an amended motion to the effect that DHS begin addressing the difficulties by first enhancing exchange of tick-infection data between diagnostic labs and DHS in order to expand the DHS tick-infection database. These data could then be incorporated into DHS' educational efforts. Dr. Kramer's alternative to Ms. Lull's first motion was finally rephrased to read:

"We recommend that DHS write letters to all public health agencies and academic institutions that test ticks urging their tick-testing data - be 1) disseminated to the press locally to enhance public awareness and 2) forwarded to DHS. DHS' letters to labs that test ticks for individuals will recommend that they also inform their public health officer and local vector-control agency, as well as DHS, when a positive tick is identified and that they specify, when possible, the site where the tick originated. Data received by DHS from these various tick-testing agencies will be incorporated into the DHS statewide database and be

made available to all contributing agencies and institutions as well as to the public.” This motion passed unanimously.

Dr. Morrow noted it will take time to persuade labs to record the site of origin of ticks submitted by individuals. He thought local health departments would be more likely both to increase local tick testing and to promote local stories to their press contacts in response to requests from interested local citizens than to requests from DHS, as they are deluged with memos from DHS about many newly emerging diseases. The Disease Control and Prevention sections of county health departments have the relevant working knowledge.

Ideas to enhance the effectiveness of press releases (PRs) were diverse. Dr. Kramer thought twice-yearly PRs, coinciding with tick seasons, were optimal because the press might be desensitized by frequent PRs, while Ms. Hubbard thought reporters might realize LD is an important story if they hear about infected ticks often enough. Dr. Stricker observed that the press is particularly responsive to controversy, citing a recent story in the Santa Cruz Sentinel about the disputed presence of infected ticks in a local state park that effectively promoted dialog between the park service and VBDS. Dr. Lane added that newly found infections and unusual infection rates also deserve PRs.

Everyone agreed with Dr. Lane’s suggestion that all VBDS PRs should include the color-coded map depicting county tick infectivity. During discussion about whether to include each county’s ranges of tick infection rates on the map, he reviewed tick-infection studies that have been done to date, noting that only one or two sites, at best, had been well-studied in any county other than Mendocino. When consulted, Ms. Hui agreed that the data in DHS’ database, while demonstrating infected ticks in most counties, are limited in that sense. Ms. Hubbard pointed to the importance of this information – that only one California county has been well studied and that in all the other counties only a few sites have been looked at, in limited samplings mostly of adult ticks. All agreed that this crucial statement should be prominently displayed on DHS’ website and included in all PRs so that information about tick infectivity is put in an appropriate context. Other decisions regarding PRs were tabled for later discussion.

Ms. Lull accepted several amendments to her second motion, and its final wording read as below. The motion was seconded and passed unanimously.

“We recommend that DHS prominently display on its website and include in its press releases about Lyme disease a color-coded map of California showing in one color counties where infected ticks have been found, and in another color counties where any *Ixodes pacificus* ticks have been found. Inasmuch as it is California’s only well-studied county, the full range of nymphal tick infectivity rates in Mendocino (1 percent – 41 percent) will be included, and the legend for the map will prominently state that the ranges of tick infectivity in other counties remain unknown because they have been insufficiently studied.”

In discussing her third motion, regarding tick warning posters, Ms. Lull acknowledged this had been discussed already and asked on the status of the postings. She noted that people go to these places, return home, and if they become ill they don't have a clue about what has happened to them (and their doctors don't either), unless they happened to see that sign. Dr. Kramer replied that DHS already provides local agencies with tick warning posters and LD brochures to post in park areas where ticks occur. VBDS posts some sites as well, particularly in campgrounds and high-use recreational areas. Dr. Lane suggested also posting areas where ticks are known to occur in habitat likely to be endemic, such as natural areas containing deer, likely reservoir animals, and ticks. The East Bay Regional Park District's numerous parklands are one such area because, in all the parklands looked at to date, his studies have always yielded infected ticks. The committee agreed to vote on the general idea and reserve discussion of further specifics such as including information on infection rates in ticks specific to the area where the signs are posted to a future meeting. The motion, amended as per Dr. Lane, read as below. It was seconded and passed unanimously:

"We recommend that DHS strongly urge, in letters to all state, local or federal parks and lands where infected ticks are known to be found, as well as where *Ixodes pacificus* ticks are found coincident with likely host and reservoir animals, that DHS post warning signs in prominent places and have Lyme brochures available for public education at these sites."

Ms. Lull also moved:

4. To counter physician ignorance and reluctance to treat, we advise the DHS to hold educational seminars featuring CA clinical Lyme specialists as the speakers and educators. These could then be taped and distributed to physician groups throughout CA. We have already obtained the willingness of these experts to participate in such a program. All DHS needs to do is set it up.

Dr. Kjemtrup said that such a videotape could conceivably be used as a product for a physician education program. All agreed the seminars and video would be only one part of a larger physician education program. Dr. Lane thought the videotape should also include a speaker familiar with tick ecology, and recommended Ms. Hui. Dr. Kramer suggested DHS partner with CA clinicians to develop educational materials. Dr. Morrow expressed concern about who would develop the educational content, using theoretical examples to show how awry things could go, and Dr. Stricker observed this would be everyone's concern. Dr. Lane and Ms. Hubbard suggested the necessary balance of controversial perspectives could be best achieved by inviting clinicians with different viewpoints to speak. Dr. Lane proposed that a subcommittee of the LDAC, including its physicians, patients, etc., could help DHS develop an educational video for physicians. It was agreed the motion required a much longer discussion that would be more appropriate under the "physician education" agenda item, and the motion was tabled until then.

IV. Discussion of DHS Brochure

Discussion of the Lyme disease brochure focused on 1) its visual elements; 2) pictures of the erythema migrans rashes (EMs); and 3) ticks and the life cycle; - and, which section had priority, given the brochure's limited space.

Ms. Hubbard asked that the brochure show either a variety of EMs or none at all, fearing that infected people might dismiss the possibility of LD should they not develop an EM or develop one that looked too different from those depicted. She had mailed the committee studies of PCR and culture-proven EMs demonstrating its great variability, including that the "classical" bull's-eye rash is not in fact typical, since central clearing occurs in only 5 percent to 37 percent of EMs.

The committee examined a variety of EM photos. Patient members and Dr. Stricker wished to include multiple examples, sufficient to demonstrate EM variability and optimize its recognition. Dr. Morrow preferred leaving EMs out altogether, observing that LD is already tied too strongly to the rash, which may occur in as few as 50 percent of infections. He found it problematic, for example, that a recent NEJM article equated the rash not appearing with infection being eliminated. Ms. Hubbard agreed the brochure needs to strongly emphasize that LD occurs without EM, but pointed out that because EM is the only indicator of early infection that is both visible and does not require lab testing, recognizing EM is currently the only way to get treatment in time to avoid development of more serious and potentially chronic illness.

In terms of specific examples of EM, the committee generally liked a photo of an EM behind the knee, a common tick bite site in adults and older children. Ms. Hubbard thought an example of an EM behind the ear, the most common visible EM site in younger children, should be included, as well as one of secondary EMs. Dr. Kjemtrup thought a bull's eye EM should be included since people who've heard of them would appreciate seeing what they look like. Lacking good photos, she and Ms. Hubbard wanted the text to further emphasize the difficulty of noticing EMs on dark skin, adding a clear description.

Dr. Kjemtrup reminded the committee that the brochure's main purpose is not for diagnostic purposes, but rather, is to present the common symptoms of Lyme disease to a wide audience to increase awareness of the disease. She, as well as Drs. Kramer and Lane, were concerned that multiple EM photos would take space away from graphics needed for the brochure's important ecological and prevention messages. Several suggestions for creating space for more EM photos were discussed, and Dr. Kramer requested a vote so there could be a clear recommendation. Dr. Lane asked how many favored:

- 1) Including multiple EM photos of variable types and shapes in the brochure, selecting representative rashes. Dr. Kramer specified "multiple" as "more than two."
- 2) Reducing but not eliminating the tick life cycle graphic to make room for the additional EM photos.

Both recommendations passed by a majority vote of hands. “Nay” votes were not solicited. Dr. Kjemtrup observed this might free up space for four or five EM photos, but probably not six or seven.

There was general agreement that every effort be made to counterbalance the powerful visual impact of using EM photos in order to make it clear that EMs don’t always develop after infection, including rearranging the brochure’s layout to place the EM photos in a less prominent position. Patient members and Drs. Morrow and Stricker stressed revising the symptoms section to emphasize 1) flu-like symptoms in early infection, mentioning that syndrome first in the symptoms section; 2) that infection sometimes occurs without any early symptoms, and 3) that symptoms are variable, changing, fluctuating and intermittent (come and go). These recommendations to DHS passed unanimously.

Further discussion on the wording and layout of the symptoms section revealed general agreement that joint pain be emphasized over joint swelling, inasmuch as the medical literature, California physicians, and the personal experiences of patient members of the committee all attest that it occurs much more commonly. Mr. Parlier and Ms. Hubbard felt readers need to be warned specifically that although flu-like symptoms and/or the rash disappear spontaneously, without treatment, the infection remains; they suggested this be addressed by listing first the early symptoms, then the symptoms that may develop if the initial disease isn’t treated.

A number of interrelated issues about the brochure remained unresolved by the close of the meeting, including:

Target audiences, primary purposes and distribution: Dr. Kramer reported that the current brochure is distributed largely through outdoor recreational areas where people are exposed to ticks, and thus is read mostly by outdoor enthusiasts. Dr. Morrow noted the largest target audience should be the general public. While it was clear that its intended audiences would influence decisions regarding the emphasis of the brochure, the committee has yet to explore whether its current distribution should be expanded.

Prevention: There was general agreement that the brochure’s primary purpose is preventing LD – through raising awareness, encouraging effective prevention practices, and emphasizing early recognition and treatment of infection to prevent later disease. Members also agreed with Ms. Merrill’s suggestion that examining oneself for ticks after exposure in tick habitat is the most effective prevention practice and should be listed first and in boldest print in the “Prevention” section. Ms. Hubbard reported that a survey of residents on hyperendemic Nantucket revealed prevention measures are practiced most regularly by those who believe Lyme is a serious disease and are confident they can detect its symptoms. General knowledge about LD did not increase the likelihood of practicing preventive measures in that study.

Tick graphics: Discussion revealed two main perspectives among committee members, leading to different opinions about which of many important ways of representing ticks deserves highest priority. Those who study ticks favored enlarged graphics of ticks that emphasize morphologic details that would help Dr. Kjemtrup and park rangers teach the distinctions between *Ixodes pacificus* and other ticks. Those who know ticks less intimately argued that its small size is *I. pacificus*' most salient feature and favored life-sized photos depicting ticks as they appear to the untrained eye. The "actual-size" graphic, in which ticks appear larger than in reality, would then be unnecessary. All thought the nymphal tick, as the cause of at least 80 percent of infections nationwide and the stage that apparently has the highest infectivity rates in California, warrants special attention. Dr. Lane reported that studies show that only about one out of five people infected by nymphs notice the tick that bit them, presumably because of its tiny size and painless bite. Non-entomologist members urged inclusion of a life-size photo of a nymphal tick in a familiar setting, e.g., on a hand or an arm. Ms. Merrill and Ms. Hubbard felt photos of adult females, more easily noticed than nymphs, could increase awareness of the presence of *I. pacificus* in an area and also help people recognize tick bites in time to prevent infections carried by that stage. They added that realistic photos of both nymphal and adult engorged ticks would help people recognize when they have been bitten. No final decisions were made about which tick graphics to use.

Treatment: Ms. Lull and Ms. Merrill observed that the current statement regarding early treatment could be misinterpreted as saying that treatment always leads to cure of the infection. Dr. Kjemtrup noted that the intent of the brochure is to provide sufficient information to ensure that the public recognizes they may have Lyme Disease and that they need to seek medical attention. Mr. Parlier and Ms. Lull argued that at a minimum the brochure needs to address differences between the treatments of early and late LD. They suggested phrasing Ms. Lull had obtained from the CDC's website and from the Texas Board of Medical Examiners, and/or stating that although antibiotic treatment of late LD is not always successful in eliminating the infection, it does provide control. No final decisions were made regarding statements about treatment.

Other Tick-Borne Diseases: Mr. Parlier suggested adding other infections carried by ticks to the list of tick-borne diseases, with a brief description of the manifestations of each, as well as the possibility of coinfections.

Ecology: Drs. Kramer and Kjemtrup observed that the tick life cycle graphic lets people know the life stages of the tick and the animals involved so that people can understand what activities put them at risk. Dr. Lane suggested adding seasonality to the life cycle graphic so people can also know when they're most at risk. Patient members suggested that the map of the State of California on the front page indicate areas where *I. pacificus* ticks and infected ticks occur. Beyond the general sense that the nymph is the most dangerous stage and should be emphasized, aspects of tick ecology and specific wording for the brochure remain to be addressed.

Vaccine: How this issue should be addressed in the brochure remains to be discussed.

Acaracides: How this issue should be addressed in the brochure remains to be discussed.

Using DHS' website as supplemental space for important graphics: Ms. Merrill, Dr. Kramer, and Dr. Stricker suggested using DHS' website as supplemental space for important graphics, including perhaps an expanded EM gallery that might include a spider-bite reaction and a tick-bite reaction, and/or an expanded tick gallery and/or an enlarged life cycle graphic.

Mr. Parlier suggested that it be stated that specific tests are used but may be inconclusive in order to focus on the need for a clinical diagnosis. He also suggested that the potential of coinfection with another tick-borne disease agent should be mentioned here since this may confound the diagnosis. Ms. Lull made the point that the need for early treatment was not emphasized enough in the brochure.

Due to the plethora of suggestions for the brochure, Ms. Hubbard suggested that subcommittees be formed to work on its various sections (the committee's physician members as well as Ms. Lull and someone from DHS focusing on writing about symptoms, treatment, and diagnosis; and others, including the entomologists and patients, on the ecology and prevention sections). Dr. Lane agreed and added that all members should feel free to join the discussions about all sections, communicating via email, to the whole committee with an eye to promoting dialogue. There was general agreement with this plan. Dr. Lane expressed his hope that when the committee meets again it will be clear which issues relating to the brochure still need to be addressed.

V. Public Comment

Dr. Lynn Shepler spoke first, asking why DHS seems to adhere to Centers for Disease Control and Prevention (CDC) policy when CDC cannot legally dictate health policy to states. She acknowledged the talented and educated DHS staff that sits on the committee, but observed that none are MDs and, in her opinion, no one was knowledgeable about LD or had adequate credentials to set policy for educating physicians about it. Dr. Kramer responded that DHS communicates and consults with the CDC on a variety of issues, however, CDC certainly does not dictate what DHS does. Dr. Kramer thanked the speaker for acknowledging the talented staff of DHS and stated that they are a very capable staff.

Dr. Shepler asked if the Vector-Borne Disease Section (VBDS) tells physicians how to treat LD. Dr. Kramer replied that VBDS does not tell physicians how to treat LD; VBDS gathers information from the scientific literature and incorporates this information into brochures and education programs. Dr. Shepler said VBDS appears to incorporate only what the CDC promotes, and she wondered why nearly every state health department just happens to follow along with the CDC. Dr. Kramer stated that there is still a lot to learn about this disease. Dr. Lane

agreed that there is no certainty and thus a lot of different opinions and the committee's extensive discussions about issues such as physician education. He emphasized that only balancing the different viewpoints would enable the committee to maintain credibility with the medical profession. Ms. Merrill asked if a physician called DHS about LD treatment, would VBDS personnel tell them how to treat LD? Dr. Kjemtrup replied that VBDS does not get such calls—most calls from physicians concern questions on risk, e.g., had LD been diagnosed from their area? No, VBDS does not tell them how to treat the disease. Dr. Kevin Reilly, Acting Deputy Director of Prevention Services, was asked by Dr. Kramer to comment on DHS policy in general. In terms of adopting CDC policies and protocols, DHS does not “do what the CDC says”. Dr. Reilly stated that the job of DHS was to look at the science and provide information that appears in the literature. DHS does not tell physicians how to practice. The information that VBDS presents is based on science and published literature. Developing treatment protocols for Lyme disease is not the job of DHS. VBDS may point inquiries to the pertinent peer-reviewed literature. DHS allows the medical community to do their work.

Stephen McFadde made the next comment. Mr. McFadde suggested VBDS investigate the possibility of “piggy backing” onto national studies like large-scale surveys, and also consider sponsoring a conference on tick-borne diseases in the southwest. If long-range planning included putting out an early call for submission of papers, scientists might begin working on the problems, perhaps stirring up some solid answers. He observed that recently “immune-privileged” bugs are emerging, infections that hide out where the immune system can't reach them, e.g., AIDS hides in T cells, Lyme hides in collagen fibers, joints and the nervous system, etc. Therefore it would be useful for chronically ill people who have physicians they've worked with for some time be able to get shot-gun antibiotic treatments without constraints occasioned by concerns about their overuse. He acknowledged that overuse promotes antibiotic-resistant bacteria, but noted that currently more than 60 percent of antibiotics goes to animal feed.

Christopher Pope stated that, as a researcher in the physical sciences, he is familiar with the peer-reviewed literature and especially how the risk-benefit/actuarial approach to science is failing. In his field, environmental research, science said for years that there was no problem, but now, as if suddenly, it is saying there is a big problem. He believes it is the same with Lyme disease, in that the influence of money creates a tendency to avoid diagnosing expensive diseases, leading to an approach to diagnosis that doesn't work, like so-called “objective” tests that don't work well and physicians saying, “the tick wasn't on you long enough.” He said the so-called “rarity” of LD is based on early ideas of what the disease is, like the blind men and the elephant, with resistance to incorporating newer ideas and information into the consensus about what the disease is. In his own case this has been costly even to insurance companies but especially to society as a whole, in that he has gone from being a productive scientist to delivering pizzas part-time, going bankrupt, and defaulting on loans.

Carol Martin expressed gratitude for the existence of the LDAC and for its members' work on the brochure. She recommended the brochure distinguish between pet-care products that actually kill ticks and those that only kill fleas, and that it include Dr. Lane's excellent picture of a robin with an embedded tick as well as his statement that "one tick lays 1,000 eggs". She recommended the committee considers maps like those available from Contra Costa County and LA West Mosquito and Vector Control Agencies, which uses dots to indicate where infected ticks have been found. Ms. Martin did not like the picture in the brochure of the ticks on a human finger because she felt this undermined the message to avoid contact with ticks. She cautioned against advising people to remove ticks from pets because people have become infected in the process. She said people just walk right by current tick warning posters, and suggested replacing them with more strongly worded versions that could state, "Don't enter this area until you tuck your pants into your socks", or the like. Finally, she suggested that Dr. Stricker be put in charge of physician education about LD.

Frank Deering stated that he has often seen DHS' cautionary signs and brochures during many trips into California State Parks, but unfortunately doctors don't frequent these places. Over 50 years of back-packing and fishing throughout California, he has removed over 50 embedded adult female *I. pacificus* from himself. After he developed persistent flu-like symptoms, doctors eliminated all other diseases, decided they were stumped and left him on his own. Fortunately Dr. LaVoie finally diagnosed him. He therefore believes DHS' emphasis should be on educating health care professionals who don't know how to do the job of diagnosis.

Cindy Watanabe asked DHS to state in their literature that LD can be acquired congenitally. She acknowledged that there is controversy about how often this occurs, but noted that her two children acquired the infection through her. Secondly, she asked that the brochure contain information about which Lyme tests are most sensitive and which are more pertinent to each stage of the disease, observing that the ELISA is often falsely negative.

Annie Konkol of the American Lyme Association (ALA) stated that she wished to create a closer focus on LD in Southern California. She said her group had surveyed CFIDS and fibromyalgia support groups in the area and found 62 LD patients who had been improperly given those misdiagnoses; several local physicians had been involved as well as a number of labs. She added that two LD cases had been diagnosed in the emergency room of a Los Angeles hospital just last month, making Los Angeles an endemic county. She stated this patient population adamantly objects to possible DHS intrusion into their medical care and privacy rights, noting that such concerns prevent the desired official reporting of cases. She feels the number of untreated Lyme patients is staggering and wondered what DHS and LDAC intend to do about it. She is concerned that there is no Southern California representation on the committee.

Cheryl S. suggested that the nymphal ticks in the brochure should be circled to draw attention to them. She asked that DHS encourage insurance companies

and HMOs not to limit the right of physicians to treat according to their conscience since society can't afford to lose people's ability to think clearly. She invited LDAC and DHS to consider what could happen if just one person loses his focus while performing a sensitive job; in some situations many people could die as a result.

Ms. Vallejo said she enjoyed the meeting and was happy with the work the committee is doing. She suggested that audio and/or videotapes be made of the meetings because many LD support group members are too ill or lack funds to attend. She added that even though DHS insists that discussing treatment is not its job, strong statements have to come from the government, especially state health agencies, to encourage doctors to lose their fear of diagnosing and treating LD. She became disabled, despite having money for her treatment, because of physician fear and ignorance. She too warned that the peer review process is tainted because reviewers depend on grants worth millions of dollars. She added that LD patients become desperate for antibiotics because antibiotics are all that allow them to feel like human beings.

Dr. Lane thanked everyone for their attendance. He stated that LDAC members see LD from many diverse points of view but try to work together because all have patients' interests at heart. He added that hopefully in a few years the LDAC would make a big difference in LD awareness and preventing LD in California. In response to a question from the audience, Dr. Lane stated that the next meeting also will be open to the public.

VI. Adjourn. The meeting was adjourned at 3:30 p.m.

Appendix I

High Hopes from the CA Lyme Disease Support Groups

Lyme Support Groups across CA and the USA refer thousands of patients to those too few physicians who diagnose and treat Lyme disease on a routine basis. Most Support Group members have chronic disease due to delayed diagnosis. This fact underscores the crying need for educated physicians who can, and do make that vital, early diagnosis.

- Our hope is that the DHS will educate CA physicians to the realization that Lyme disease exists in CA.
- Our hope is that the DHS will make early diagnosis and treatment a reality by educating physicians to the varied presentations of Lyme disease.
- Our hope is that physicians will be free to treat us as symptoms dictate... not insurance companies or medical boards.

The obvious key to early diagnosis and treatment is physician ability to diagnosis. But there are two major reasons why this is not so: ignorance and fear.

Ignorance: Many doctors truly believe that Lyme disease does not occur in their city, or their county---in just about every city and county in CA! Many doctors think Lyme disease is only an arthritic disease, and are unaware of the multitude of neurological, vascular, and other presentations. Many doctors think that a negative **ELISA rules out** infection. Many doctors mistakenly think that one must have an **EM** to have the disease.

We must reeducate physicians to the awareness that the hallmarks of this spirochetal illness are multi-system and the often subjective symptoms that wax and wane.

Fear: Insurance companies and medical boards have been known to instill fear in the heart of many a Lyme doctor. We know of CA physicians who rarely order IV antibiotics for their neurological Lyme patients due to this very real fear. Others are afraid to treat beyond an arbitrary point published as a guideline by some august body, in essence deserting their still symptomatic patients. Those who treat us symptomatically are frequently harassed. **(See Exhibit A)**

In addition there is a peculiar attitude in the medical community that sneers and looks askance at a Lyme disease diagnosis and ostracizes those doctors who diagnose and treat to any large degree. Peer pressure, in an occupation where it took ten years to accept a novel thought like ulcers being caused by *H pylori* infection, has got to be a significant force. And not many physicians are comfortable making a clinical diagnosis based on primarily subjective symptoms.

The dichotomy of attitudes about this disease: On the one hand Lyme disease is often made out to sound like an insignificant illness that is easily treated in three weeks. And at the same time there is an overwhelming amount of continuing research on it worldwide; drug manufactures are scrambling over each other to produce moneymaking vaccines to prevent this “innocuous” disease. Logic dictates that it just can’t be both ways, and of course chronic Lyme patients know it isn’t. Innocuous diseases do not provoke mandated vaccines and expensive research.

The Lyme Support Community has hopes that at the very least DHS will incorporate the following into their Lyme disease educational programs (website and brochures and educational seminars):

- 1) Everyone, physicians included, must be educated to the fact that Lyme disease exists in CA. If DHS prominently publicizes lists of those counties where infected ticks have been found, it will go a long way toward validating and substantiating the existence of Lyme disease in CA. This is not a question of degree of infectivity or exact sits of the infectivity... Just the mere fact that: **Lyme disease does exist in CA... here is the proof.**
- 2) Everyone should be made aware that both ticks and patients have travel histories.
- 3) Everyone should be aware of the multiple coinfections with Lyme disease that can complicate the course of the disease and treatment.
- 4) Everyone should know that the pathophysiology of Lyme disease is still largely unknown.
- 5) Everyone should be aware of the multi-system presentations of Lyme disease that wax and wane, and that EM, although pathognomic for infection, **DOES NOT** occur in all cases.
- 6) Everyone should know that diagnosis and treatment are an inexact science at best, due to a lack of reliable objective tests. The ability to make a Clinical Diagnosis is mandatory!

Indirect tests that measure antibodies are not reliable. ELISAs and Western Blots can be negative and yet infection can be present.

No one knows when the disease is truly present or vanquished: it is difficult to rule out. Latency and relapse do occur.

Treatment modalities vary with the individual, and stage of illness. Lyme is not always easy to cure or control.

Vaccines are not the solution. They neither address nor erase the need for a reliable test and cure.

Multiple strains and species of *Borrelia* confuse the issue.

- 7) **Early diagnosis and treatment are the best chance for cure**, but symptomatic treatment with antibiotics for chronic and tertiary disease can be palliative.

In conclusion the Support Community hopes that the DHS can make this minimum amount of information (1-7) known throughout CA and that this information, disseminated under aegis of the state, will offset the monied interests that strive to dictate and limit how our physicians treat us.

(Exhibit A) Excerpts from February 2001 e-mail from a Lyme Support Coordinator in CA

Dr. X was notified by his medical director that he was being called into their medical review board for a hearing on his use of Rocephin, and for the over diagnosis and treatment of LD. The purpose of the hearing, they told him, was for him to explain his use of such expensive treatment. He has patients on long-term IV for severe neurological symptoms. He just found out last week that Dr. Z, practicing in his same group and who is known for his anti-LD attitude, had turned him in! Dr. Z has had numerous patients with positive Western Blots that he has told they did not have LD, as there was not a problem with Lyme in this County!

It would be great if you would bring this to the Advisory meeting- this treatment of our physicians has got to stop!